Emerging dynamics of evidence and trust in online user-to-user engagement: the case of 'unproven' stem cell therapies.

Abstract: This article explores the ways in which patients and their families (hereafter referred as users) share and evaluate disease-specific evidence via online communities. The aim is to understand what this user engagement in healthcare and knowledge production reveals about society's shifting perceptions of trust in the institutions of 'evidence-based medicine' (EBM) such as regulators, bioethicists, and scientists and the implications for EBM. To do this, I use the case of experimental stem cell therapies (eSCTs). ESCTs are commonly labelled in academic literature as 'unproven,' a label that frames their lack of conclusive clinical evidence as unsafe, inefficacious and thus unethical when clinically used. Despite this framing, users engage with other users to share and evaluate all available evidence for themselves, including on-going clinical trial and experiential evidence to build trust for and undertake eSCTs. Increasingly, this user engagement with evidence takes place in online communities that range from user-created and user-run *Facebook* pages to user-to-user discussion forums on healthcare provider sites or blogs with little if any provider-input in conversations. In this paper, I draw on a sample of these user conversations to show the complex and unpredictable ways in which what counts as evidence and how trust is built for it are shifting. In so doing, I reflect on the shifting relations between the institutions of EBM and society for greater control over evidence.

Introduction

In 2012 and 2013, two large-scale surveys of healthcare trends in the US (by *Pew Research* and *PricewaterhouseCoopers*) attempted to quantify an emerging trend of online health information seeking among patients and their families; or what I call user-to-user engagement. The *PricewaterhouseCoopers* (2012) survey found that 32% of adults used social media to follow family or

friends' experiences of illness and disease. Twenty nine percent of adults sought information related to other patients' experiences with their disease and 24% viewed health-related videos or images posted online by patients. This article explores the dynamics of online user-to-user engagement in healthcare and knowledge production in the specific case of experimental stem cell therapies (eSCTs), for which a majority of patients and their families (hereafter referred to as 'users') build trust for eSCTs through online communities. The aim is to help understand society's shifting perceptions of trust in the institutions of 'evidence-based medicine' (EBM), such as regulators, bioethicists, scientists, etc. (hereafter referred as 'providers') and the implications of these shifts for EBM.

Since the 1980s, social scientists have focused increasing attention upon the relations between science and society in the wake of growing mistrust in scientific knowledge and expertise (Leach, Scoones, & Wynne, 2005; Putnam, 1993; Starr, 1982; Wynne, 2006). Critical scholarship challenged the 'deficit model' that informed efforts to engage publics; a model which assumed that mistrust was due to ignorance or a 'deficit' in knowledge rather than critical thinking and the co-existence of other ways of knowing (Wynne, 2006). Partly in response to this critique and to a combination of large-scale citizen mobilisations (e.g. surrounding HIV/AIDS research in the 90s) and growing discursive engagement with "more traditional ways of knowing medicine" like experiential evidence (Djulbegovic, Guyatt, & Ashcroft, 2009), more participatory models of EBM integrating experiential evidence have since emerged and become widely practiced, particularly in downstream healthcare settings (Charles, Gafni, & Freeman, 2009; Miles & Mezzich, 2011; Tonelli, 2006).

Against this backdrop, the Internet has generated novel possibilities for publics to engage with evidence and medicine. One such example is the emergence of online communities dedicated to sharing and evaluating the credibility of all available disease-specific evidence including scientific and experiential evidence. What do these spaces reveal about the relations between scientific evidence (from basic research and clinical trials), public trust and scientific evidence as a basis for

policy? This paper presents societal engagement from *Facebook* pages and discussion forums surrounding the clinical use of eSCTs. These online spaces can be thought of as online communities in which users share and evaluate available evidence to build trust in eSCTs, alongside traditional provider-based sources of trust-building, such as physicians. For instance, disease-specific discussion forums attract users on the basis of shared (disease-specific) interests and help foster kinship and knowledge sharing (e.g., discussions on *MS Society UK*) (Wright & Street, 2007). Nevertheless, it is important to emphasize that online user-user engagement represents one increasingly relevant perspective, and not the entirety of experiences and views.

What is notable about these communities for our purposes is the absence of input from 'providers.' I will show that, in a context where eSCT users are viewed as ignorant or gullible (Qiu, 2009), these online spaces can be read as productive sites of user empowerment in producing and evaluating evidence for user choice of eSCTs (Andreassen & Trondsen, 2010; Lupton, 2013). By drawing attention to communities that do not actually want to be 'engaged' by providers, this article offers the provocation that the logic of participation and inclusiveness in existing community and public engagement models may not have gone far enough. Through relating user activity in online user-to-user engagement, this article explores <u>why</u> and <u>how</u> people produce, evaluate and build trust for evidence. As I will show, users do not simply disfavour scientific evidence in favour of experiential evidence, but rather combine these and other sources of evidence in complex and unpredictable ways. This article, therefore, casts online communities as productive epistemic spaces (in the sense of Haas' (2001, p. 11579) epistemic actors with "agency in politics and policy formation"), which signal a shift in what counts as evidence and how trust is built for this evidence.

Dynamics of user-to-user engagement

Contemporary public engagement is intended to foster dialogue between policymakers and policy takers and to engender mutual trust. However, critical scholarship has suggested that engagement

practices have been and continue to be mere tokenistic gestures by providers inline with "fashion-following" political rhetoric, and thus largely ineffective in rebuilding public trust (Wynne, 2006, p. 217). Wynne, for instance, showed that expert policymakers were instead interested in downstream "instrumental concerns about impacts...[and how] these can be identified, and represented, adequately by scientific risk assessment" (Wynne, 2006 p. 218).

In particular, in the context of emerging technologies, there is a long history of contestation over the rights of technology end-users, which has intensified in the last decade (for an exhaustive discussion, see Smith et al., 2017). Consider for instance the case of AIDS activism in the 1990's, which highlighted this chasm in the understanding of end-users between provider's imagination of a future user and users' lived experiences (Epstein, 1996; Lambert, 2013). Recent scholarship has sought to bridge this chasm with 'user-centred' technology design based on user experiences instead of "edited renderings" of the image of the user to suit specific professional or technological uses (Hyysalo & Johnson, 2015; see e.g., 'human-centred design' in Bazzano, Martin, Hicks, Faughnan, & Murphy, 2017).

In policymaking, the enactment of 'Right-to-Try' legislation nationally and across thirty-seven US states since 2014, which allow terminal patients the 'right to try' experimental treatments without seeking prior FDA approval (Brennan, 2017), highlights this increasing focus on technology end-users. Nevertheless, 'Right-to-Try' laws remain at its heart an "access debate" (Dresser, 2015) even though they highlight tensions between expert and lay interpretations about the adequacy or accuracy of available evidence in private treatment choices (Pear & Kaplan, 2017). Thus, to what extent access based considerations in policy like the UK's *Early Access to Medicines Scheme* launched in December 2014 will translate to meaningful considerations of lived experiences in the evidence basis of EBM remains unclear (Facey, Boivin, Gracia, Hansen, Scalzo, Mossman, & Single, 2010; Greenlagh, Snow, Ryan, Rees, & Salisbury, 2015), although the case for a "compromise policy" integrating experiential evidence in policymaking is emerging (Matthews & Iltis, 2015).

At the same time, as the *PricewaterhouseCoopers* (2012) survey data presented in the introduction suggest, when it comes to disease-specific evidence and treatments, users are increasingly engaging with other users to seek and share lived experiences (hereafter also referred as 'experiential evidence'). Moreover, this engagement is sought and fostered in user-to-user relationships with little or, no recourse to provider-side inputs (Lupton, 2013). To understand these dynamics of evidence and trust in emerging user-to-user engagement, the contestation between scientific and experiential evidence in eSCTs provides an excellent case study.

Experimental stem cell therapies

Except for a handful of SCTs approved for public marketing, most remain experimental (i.e., lacking conclusive evidence of clinical safety and efficacy) and unavailable to the Euro-American public through public healthcare providers like the UK NHS and the US Medicare. However, eSCTs have been and continue to be available in private clinics in the global south (Lau, Ogbogu, Taylor, Stafinski, Menon, & Caulfield, 2008) and increasingly in OECD countries (Turner & Knoepfler, 2016; Berger, Ahmad, Bansal, Kapoor, Sipp, & Rasko, 2016). Since the early-2000s, media coverage of the immense potential of stem cells as a 'miracle cure' created public demand for eSCTs (Ramesh, 2005). The result was that Euro-American seekers of eSCTs not only started travelling beyond their home countries to access eSCTs but also, in the absence of clinical evidence, started to seek and share experiential evidence to evaluate the benefits of eSCTs for themselves. In turn, providers used the term 'unproven' to describe eSCTs, highlighting public access to them as unsafe and unethical based on their lack of conclusive clinical evidence of efficacy (ISSCR, 2013; Lau et. al, 2008; McLean, Stewart, & Kerridge, 2015).

On the one hand, the effect of a negative label like 'unproven' instead of a label like 'experimental' for experimental SCTs is that 'unproven' not only casts eSCT practitioners as charlatans but also frame users as 'gullible' and lacking the capacity to make good health choices (Qiu, 2009) without provider intervention (Master & Resnik, 2011). Thus, the construct of

'unproven' not only assumes a moral high ground that presupposes scientific evidence as the only legitimate way of knowing therapeutic safety and efficacy but also public trust in its legitimacy. In this sense, 'unproven' frames public trust in eSCTs within the boundaries of scientific evidence and delegitimises those stepping beyond those boundaries when considering 'other' forms of evidence like user experiences (ISSCR, 2008).

On the other hand, the agency of eSCT users who "bypass" warnings by the "institutions of stem cell science" is increasingly studied (Salter, Zhou, & Datta, 2015; p. 162; see also Chen & Gottweis, 2013; Lupton, 2013), particularly in studies of how users build trust for experiential evidence through online user-user communities (Bharadwaj, 2012,p 312; Foster, 2016; Kallinikos & Tempini, 2014; Rachul, 2011). For *instance*, Petersen, MacGregor, & Munsie (2016) used the lens of the televised experience of Kristy Cruise – an Australian patient who had travelled to Russia to undertake eSCT – to shed light on the increasingly important role of digital media in shaping hope-risk expectations among users. Perhaps more than anything else, Petersen et.al (2016) highlighted the disease-specific communities that form around similar concerns with evidence and which this paper explores to understand why and how these communities engage with each other, and increasingly through online environments (see e.g., Aubusson, 2014 in McLean et al., 2015). Indeed, Sharpe, DiPietro, Jacob, & Illes' (2016, p.441) finding that among "individuals interested in stem cell tourism ...internet was the most commonly cited source for information-seeking, ...[with most using] stem cell clinic websites [and] social media," emphasizes the need to understand the emerging dynamics of online user-user engagement. This paper extends this growing body of work to understand why and how users 'step-out' beyond the notion of 'unproven' to evaluate for themselves the credibility of both scientific and experiential evidence via online communities; evaluations of what 'experiential data' is shared, provide opportunities for future research. This paper also extends the surveys by *Pew Research* (Fox & Duggan, 2013) and *PricewaterhouseCoopers* (2012) by exploring why user-to-user sharing of disease-specific evidence is happening and how it is building trust in certain kinds of evidence. As this form of engagement is increasingly mediated through online communal spaces like *Facebook* and

discussion forums, a sample of user-to-user conversations in these spaces are studied to answer these questions.

Method

Sampling and data collection

In this study, I used two search methods to draw a sample of user conversations. First, using the online *Facebook*-page ranking tool *Socialbakers.com* which ranks pages by user visits, I ranked the most user-visited *Facebook* pages using the search term 'stem cell therapies'[i] (referred to in data extracts below as File1). The search returned 61 *Facebook*-pages of which eight were chosen after excluding others based on exclusion criteria including fewer than five user-visits or content relating to non-medical applications such as cosmetic surgery. Of the selected eight *Facebook*-pages, four were moderated and run by patients' families, three by eSCT clinics and one by a private medical tourism facilitator. Second, I took a disease-specific approach, focusing on the top three websites on Multiple Sclerosis (MS) (excluding provider websites offering eSCTs) that users see when they Google 'stem cell therapies multiple sclerosis' namely, the *National Multiple Sclerosis Society* (www.facebook.com/nationalmssociety; 358 of 818 posts; 2014-2016), the *MS Society* (www.mssociety.org.uk; 69 of 818 posts; 2011-2012), and *The Niche* (ipscell.com; 141 of 818 posts; 2012-2016) (referred to in extracts below as Files 2, 3 and 4 respectively). MS was chosen based on Berger et.al.'s (2016, pp. 160–161) survey of the "top [30] conditions treated by all clinics and academic centres" worldwide for eSCTs. The final sample had 818 posts and 20 testimonials drawn from eight Facebook pages and three websites between 2011 and 2016.

This dual search method mimicked the search pattern typically employed by users as identified through informal conversations with eSCT-patients at a private clinic in Delhi, India. The logic of the searches was that, while the Facebook-search gave users an array of user-created and -run conversations relating to all conversations in SCTs, the disease-specific search provided disease-specific information and conversations on provider-run sites. Moreover, this sample of *Facebook*

and discussion forums is appropriate for this research as both platforms allow users to engage with each other over the long term and forge communities (unlike e.g. *Twitter's* event-centric public engagement) and is consistent with Sharpe et.al's (2016,p. 441) findings of online community engagement trends in eSCTs. Importantly, this search method is emblematic of the ways in which the geographies of these online communities map into the lived experiences of users who travel globally to access eSCTs unavailable at home.

Analysis

The qualitative data analysis software *Atlas-ti* was used to organise thematic coding of the sample. Codes were derived inductively from my thematic analysis and the broad themes that emerged included issues of trust, distrust, betrayal, sense of victimisation, risk awareness and rationalisation, knowledge gain (and its sources) and knowledge sharing.

Ethics and limitations

A key limitation was that the *Google* search (in the disease-specific approach) generated an abundance of data in excess of one million results, from which only the top three sites were studied. This means that other sites could have revealed data important for this research but could not be studied due to human cognitive and time constraints. Another limitation, as with any social-media research, was the possibility of data inaccuracies arising from (a) 'exaggerated views' posted online, (b) differences between online and 'real-world' behaviours enabled by "[user] anonymity" on the internet (Beninger, Fry, Jago, Lepps, Nass, & Silvester, 2014) and (c) distortion by fake user accounts. Large social networks including *Facebook* were already using dedicated staff and various fake-account detection tools like *SybilsRank*[xii] as far back as 2012 (Cao, Sirivianos, Yang, & Pregueiro, 2012), although their effectiveness remains questionable. To reduce fake-account distortion, the research used participant 'views', which were repeatedly reflected across the web pages/sites (greater 'n') at different times by different participants. Lastly, this research was limited to English-language content because social media analytics applications like *socialbakers.com* are algorithmically limited to English content. Interestingly, there

were no discernible language proficiency issues because a *Google* search conducted from a UK-based IP address (in an English-speaking region) is designed to return English-centric results - which is limiting. However, reconfiguring Google to each linguistic-region of the world was unfeasible. As regards research ethics, informed consent was deemed unnecessary as (a) only material in the public domain were used and (b) usernames were anonymised (blanked) where direct quotes are used or where possible data was presented in aggregate or paraphrased in accordance with anonymity and 'no harm'-requirements (Markham & Buchannan, 2012).

Why users step out beyond the boundaries of 'unproven'

Conversations revealed that participants stepped beyond the boundaries of 'unproven' to evaluate the trustworthiness and credibility of evidence. Decisions to do so were tied to distrust in processes, actors, and institutions underpinning scientific evidence, especially those perceived to have commercial linkages, but did not extend to distrust in scientific evidence itself. Participants widely believed in the systemic collusion between 'big pharma' (perceived as dishonest) and regulators, in particular, the US Food and Drug Administration (FDA). The belief that the FDA – the "protector" of public interests – was colluding against them engendered distrust and a sense of betrayal by institutions of scientific evidence perceived to have significant conflicts of public-private interests (File2, File4). Participants viewed themselves as victims of the profit-driven pharmaceutical industry, which, in collusion with regulators, were perceived to profit from the 'sickness industry':

> The FDA is just in the hip pocket of Big Pharma. Too many drugs [have] been put out as safe and later people are dying from them. As adults we should have a little more freedom to make our own health decisions (File4-January/2012).

> ...big pharmaceutical companies won't allow a cure. Too much money to be made keeping people sick (File2-June/2016).

Prominent recalls of drugs which had been granted market authorisation by leading regulators such as the FDA, despite the clinical evidence on the contrary, was viewed by participants as instances of regulator-industry collusion against public interests. In stem cells, the *Regenex*[iii]-v-FDA case – where the US courts' ruling in favour of FDA regulating *autologous* (patient's own) stem-cells like drugs led to state-public contestation (Eisenstein, 2016) - was viewed by participants as evidence of the FDA's collusion with 'big-pharma' to control and thereby profit from the human body. As one participant summarised:

> ...FDA is in bed with the Pharmaceutical, they have been for decades. They have approved thousands of 'legal' drugs on the market, which has resulted in millions of deaths around America, through prescription drugs. ...to say stem cells are drugs is a complete and utter nonsense, it is an organ transplant. It has NOTHING to do with FDA or being a drug. In fact the FDA have persistently tried to shut down all stem cell activities as it is threatening their playground of manufacturing hard drugs and keeping people sick, as opposed to treating them once and for all. Wake up people!!! (File4-January/2012).

> Until FDA can figure out how to make money on this, people will suffer financially and in health! (File4-December/2013).

The phrase 'FDA' appeared 35 times among 141 posts in response to the "Top 10 list of important, easy-to-understand facts for patients about stem cell treatments" written by a stem cell scientist on a popular stem-cell advisory blog (File4). Only five (of 35) times 'FDA' appeared was it alongside a positive view. This suggests that the erosion of trust from the perceived conflicts of interest around institutions that legitimise scientific evidence such as the FDA had motivated trust for therapies distrusted by those institutions. As one user noted:

> Just because it is "unproven" by FDA standards does not make it a scam. ...Everyone should do their homework and do what is best for themselves (File2-October/2015).

Thus if the negative label of 'unproven' frames public trust in eSCTs within the boundaries of scientific evidence and delegitimises those stepping beyond them, then questioning that label (as in the quote above) reflect at the very least (a) cognisance among participants about other ways of knowing or 'proving' and (b) agency to evaluate who can(not) be trusted. Intuitively, that this evidence evaluation was conducted in online communities almost devoid of provider inputs, revealed user-distrust in most providers as self-serving rather than public-interest serving:

> ...'experts' voiced the concern that so many people trusted you tube more that the CDC - FDA etc. That is the problem we don't trust officialdom. ...XXX's survey ...suggested only one percent of us trust officialdom (File3-December/2011).

The result of this is a form of user-to-user engagement that is unlike traditional provider-user models of participation premised on providers sharing power with users. Indeed, participants extended and attributed their distrust of providers onto experts by insinuating their collusion with 'Big Pharma' through examples reflecting conflicts of interest; especially targeting experts highly active in calling for global regulatory strengthening against eSCT's. For instance, one participant accused the provider and site-owner of a popular discussion forum of such conflicts of interest:

> Doing the work that you do, you are too sophisticated to be ignorant of the actions of the FDA in serving Big Pharma and Big Medicine at the expense of the patient. The only possible explanation for your statements is your collusion and/or your financial dependence. Your statements betray you. (File4-January/2012).

In sum, participants' evaluations of evidence were shaped by distrust in the commitment of EBM's institutions to protecting public interests, especially those individuals and institutions with private or commercial interests. This distrust followed from the reverse logic that if 'unproven' SCTs were demonised by 'untrustworthy' providers, then eSCT practitioners could not be in collusion with Big Pharma - and thus they were worthy of re-evaluation and possibly worthy of trust as well. A key part of this logic was to establish the untrustworthiness of some providers, and this was done by citing instances of provider-industry collusion, corruption among scientific insiders and by discrediting expert credentials with proof of conflicts of interest (File2, File4). This suggests that distrust in some providers motivated some participants to step beyond the provider-constructed definition of eSCTs to evaluate all available evidence for themselves. Notably, distrust in providers is not the only reason that motivates user choice of eSCTs but adds to a host of complex and diverse reasons like illness severity, access restrictions to treatments, etc. explored elsewhere (see, e.g., Salter, Zhou, & Datta, 2014).

How users evaluate evidence

Participants evaluated a range of available evidence, including physicians' advice, experiential evidence and scientific literature. For instance, the discussion threads on *The Niche* and *MS Society UK* mentioned "published/publication/pub-med" 11 and 14 times respectively (File4 and File3). One participant offered the following sources (at times with hyperlinks) to help other participants to research treatment choices in Multiple Sclerosis (MS):

> ...UK-NICE [guidance document]; Centonze etc. of University Hospital Tor Vergata (Rome); the Annals of Neurology, July 2011 (pub-med), MS Matters, Pub-Med (4 times), UK Parliament publications, Cochrane Summary and Monto et.al Report 2008 (IEP.org) (File3-October/2011).

Apart from the scientific research articles discussed above, participants also expressed trust in publications by entities such as the *Cochrane Collaboration*,[iv] which provides reviews of diverse

conditions based on aggregates of diverse evidence. Overall, participant comments revealed high degrees of trust in basic research papers and publications from sources perceived as trustworthy like *UK Parliament* papers and *Cochrane Collaboration* analyses.

Participants were interested in educating themselves in the science of MS by extensively and exhaustively triangulating their knowledge through searching, monitoring, researching and at times following basic research study results (e.g. cohort studies) over years, often remarking: "...I have researched so much..." or "I have been researching this for a while and reading on everything I can" (File2-October/2015). One outcome of this was that discussion forums of large disease societies and patient organisations were used by users as knowledge repositories to share and learn about competing views, new research, on-going trial information, members' disease progress (or recovery) and more. In turn, participants used this resource to evaluate media coverage of 'unproven' eSCTs. As one participant commented,

> All too often new treatments are 'glamourised' - there is nothing easy or fool proof! (File2-October/2015).

Some participants also expressed a preference for reading scientific findings informing media coverage (File3-October/2011). Thus suggesting critical evaluation of evidence amongst users that challenge assumptions of information deficit underlying 'gullible' user choices of eSCTs (Master & Resnik, 2011).

Participants requested, shared and empathised with other users' views, evaluations and disease experiences. The *Facebook* page of the *National MS Society* (USA) was one of the most frequently searched pages under the search term MS and contained 15 requests for information about eSCTs. Below is a typical solicitation for further information on discussion forums:

> Hello All, I have recently come across a treatment for MS - CCVSI. It is an operation, which unblocks veins to allow blood flow. It isn't available in the UK but can be done in Poland and some other countries. Has anyone else heard anything or had this treatment???? (File3-October/2011).

The solicitation elicited 67 comments, including five comments about disease experiences and four about 'collusion between pharma and regulators.' It also included 24 comments *for* and 26 *against* experimental therapies. Thus, it was not the case that users only shared or heard 'positive' experiences. On the contrary, users had a high awareness of the risks of eSCTs and evaluated therapies based on individual risk-rationalisation calculus' typically combining low tolerance for 'safety' risks with high preference for 'efficacy' risks as below,

> I have been researching this for a while and reading on everything I can the death rate is less than 1% (Evaluating 'safety risks'; File2-October/2015).

> ...the acceptable risk to the NHS is 1%, the risk so far for the CCSVI intervention is about 100 times lower than that. Some 30,000 people world wide have been treated, only three people have died and a handful have suffered some complications (Evaluating 'efficacy risks'; File3-October/2011).

Consequently, participants viewed eSCTs as a way of 'improving' quality of life while 'hoping' for cures. The discussion thread on *National MS Society* contained 32 (of 358) posts expressing hope and prayers for a future cure, 23 posts expecting stem cells to improve quality of life and zero comments indicating expectations of a cure from eSCTs. Similarly, while patients expressed trust in eSCTs and wanted others to trust in them, they were careful to convey realistic expectations:

> Like anything else, HSCT doesn't work for 100% of patients, but it works for a very high percentage (File2-June/2015).

> What works for one doesn't for another. No two cases [are] alike as [X] said. ...Just don't turn people off from something that may work wonders for them. (File2-October/2015).

Negative views or experiences were shared and viewed as important in participants' evaluations of evidence. As one commented:

> ...it doesn't work for everyone, and it certainly doesn't do the sort of things that you have a tendency to claim because people DO relapse and DO progress while on it; in fact some people get a lot worse (File3-December/2011).

Users, in turn, suggested bolstering eSCTs with mainstream medication and wellness regimes for improved results:

> "Every single person has to find their 'combo'. One size does not fit all... Genetic, vaccine, diet and environment play a part. ...It [i.e. HSCT] requires 35+ treatments to be effective. I was treating a frontal lobe brain injury, MS and migraines = gave me a new life!" (File2-June/2016).

These conversations highlight the simplistic nature of the view that 'unproven' therapies victimise users who are thought to be gullible (Qiu, 2009) and lacking the capacity to make good health choices without provider intervention (Master & Resnik, 2011). Participants not only conducted exhaustive reviews of disease-specific evidence but made rationalisations of risks and benefits in their individual cases. Indeed, the finding that users access an array of information is consistent with Sharpe et al.'s (2016, p. 445) finding that users engage in "multi-level information-seeking." This, in turn, questions the provider presupposition that "the portrayal of stem cell medicine on provider websites [as] optimistic and unsubstantiated by peer-reviewed literature" may lead users

to make poor treatment choices (Lau et.al., 2008). For it assumes weak user decision-making processes mostly informed by and dependent on positive provider feedback without considering the complexity and array of sources that users reference.

However, what is conspicuous by its absence (in the conversations analysed here) is the reference to provider-created public advisories warning users against undertaking eSCTs as well as academic papers by bioethicists or sociologists. This absence suggests that users rely on evaluating basic research evidence themselves or its interpretations by large credible bodies with public accountability (e.g. UK Parliament reports) and experiential data from other participants. Indeed, provider constructions of what constitutes 'evidence' (e.g., in provider-run online public advisories warning users against 'unproven' therapies) did not constitute a part of users' evidence base (as shown in the previous section). This suggests that users appeared to have strong trust in basic research findings but not in provider constructed interpretations of its significance for them. At the same time, users placed a high value on experiential data shared in user-to-user settings when evaluating the trustworthiness of evidence for eSCTs. The latter is not surprising because studies show high degrees of trust in small-group 'community' settings when people know each other and where there are fewer chances of 'free-ridership' and 'cheating' (Artinger & Vulkan, 2016; Dietz et.al., 2003).

Conclusion

In this paper, I explored why and how people are evaluating 'evidence' themselves through online user-to-user engagement. First, I showed that users' choice to evaluate evidence for themselves is grounded in deep distrust in some provider's commitment to protecting public interests. The underlying logic is that if the untrustworthy institution's distrust 'unproven' therapies then eSCTs are at least worthy of evaluation and possibly worthy of trust as well. This trust for eSCTs also points towards the underlying logic of why user-to-user engagement excludes providers who are viewed as untrustworthy. Second, I showed that distrust in providers could not be conflated with distrust for scientific evidence. On the contrary, users demonstrated high levels of trust in (a)

basic research evidence (but not in provider constructed interpretation of its significance for them), and (b) experiential data shared between participants in user-to-user conversations. In effect, this article casts online user-to-user communities as productive epistemic spaces that are challenging the view propagated by providers that scientific evidence is the only legitimate form of knowing or 'proving' therapies. As I have shown, users combine abstract scientific evidence with lived experiences in complex and unpredictable ways. This shifting public perception of what counts as evidence and public trust for who says what counts as evidence not only calls for greater objectivity in presenting clinical evidence as one among many ways of knowing but also for greater user control over upstream evidence generation (Wynne, 2006; Lambert, 2013).

That people trust people and rely on forming an opinion from a wide array of evidence as the data suggest, rather than blindly trust provider constructions of evidence, is evident. In turn, this highlights the shifting relations between the institutions of EBM and society, in which lay people are exerting greater control over the evidence that lies at the heart of evidence-based drug development policies. For if users are increasingly making their own evaluations of evidence with the result that they not only trust eSCTs but are accessing them by travelling beyond the jurisdiction of Euro-American policies that prevent and dissuade access to eSCTs, then for these users at least, these policies have little relevance. This implies that for providers to remain in touch with publics, there needs to be greater inclusiveness in the ways in which upstream institutions of EBM engage with users.

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Notes

[i] Search included substituting 'therapies' with 'treatments'.

[ii] http://css.csail.mit.edu/6.858/2014/readings/sybilrank.pdf.

[iii] US-based private clinic offering eSCTs for orthopaedic conditions.

[iv] http://www.cochrane.org/CD009956/MS_exercise-therapy-fatigue-multiple-sclerosis

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